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The rise and rise of parents' groups

by Josie Appleton

It often appears that parents who lost children have been the driving force behind the investigations into alleged medical malpractice at the Bristol and Alder Hey hospitals in the UK.

The high proportions of child deaths from heart surgery at the Royal Infirmary in Bristol, and the retaining of organs from children without parents' explicit consent at Bristol and Alder Hey hospitals, were found by inquiries to be the consequence of doctors' arrogance and unaccountability - ending with calls for new systems of regulation of the medical profession.

The government seems keen to convey the impression that parents are behind the calls for medical reform. At the government chief medical officer's summit on organ retention on 11 January 2001, chief medical officer Liam Donaldson presented himself as a placid chair, there only to convey the views of parents: 'I have been asked to provide advice to the secretary of state [on how to change policy]. I have got a blank sheet of paper.... We particularly want to hear from the representatives of the families affected', he said (1).

In the conference summing up, BBC science and health correspondent Fergus Walsh made his point explicit: 'That piece of paper should be full of ideas from the people who have been speaking here today. The families will accept nothing less than a change in the law.... We should listen to the families more than we listen to the doctors, more than we listen to the Royal Colleges...because it is the families who have been through this.'

At the summit, parents appeared as public figures demanding change. Stephen Parker, chair of the Bristol Heart Children's Action Group (BHCAG), said that the Bristol scandal 'rocked the medical establishment and has at last empowered patient groups to ask questions and get answers'. Michaela Willis of NACOR (National Committee Relating to Organ Retention) said that the summit 'should be driven by the public's requirement for change': 'NACOR, we feel, gives the public a voice.'

Representatives of parents' groups went on to deliver strident calls for reform. John O'Hare from Pity II Parents Support Group (Parents who have Interred Their Young Twice) in Liverpool (2) called for new legal regulation of the medical profession: 'Guidelines are not enough. It has been proven that they have been ignored. Self-regulation by the medical profession has been shown to be inadequate. We must have changes in the law' - a comment given prominence in the introduction of the chief medical officer's final advisory report.

Lynne Langley from the Stolen Hearts Group criticised the fact that 'clinicians continue

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to act in an arrogant manner by deciding what information the parents should be given by post mortem'. Stephen Parker called for the immediate implementation of the recommendations of the Bristol inquiry: 'It is in your hands, Professor Donaldson, to deliver this for us. The Bristol families...have done their part.'

Donaldson came across as the mere receptacle for these demands, filling up his blank piece of paper as he was told. 'Thank you, Stephen', said Donaldson, you 'have given very wise advice to us'. 'Thank you....that was a beautifully clear analysis of your experience and the lessons that should be taken from it and some very important pointers to the future', he told Lynne Langley. At the end of the conference Donaldson apologised to the parents on behalf of the NHS - 'but an apology is not enough. What you need to see is *action flowing from your experiences, and action that will change the things in a major way...we do have to change the law. We do have to put in measures that bite and work*' (emphasis added).

Donaldson's self-presentation could seem a little disingenuous, given that the views expressed by these parents chime with the policy of the New Labour government and their allies in the medical profession: the introduction of new forms of regulation of doctors. As Dr Michael Fitzpatrick has outlined on *spiked*, the government is working towards the introduction of a comprehensive framework of bureaucratic regulation of medical practice (3) - a project that was launched under the banner of 'clinical governance' in the December 1997 white paper, *The New NHS* (4).

Donaldson himself argued the case for new systems of 'appraisal and assessment of [medical] performance' and new disciplinary procedures for doctors in his 1999 consultation document, *Supporting Doctors, Protecting Patients* (5). Ian Kennedy, appointed by the government as chair of the Bristol inquiry, demanded back in 1980 that 'a wholly new system of supervision and sanction must be created' for doctors.

So how did the parents who spoke at the chief medical officer's summit come to the same conclusions as the government? There is, after all, no spontaneous leap from being told that your dead child's organs have been retained without your knowledge, and the resurfacing of grief that ensues, to demanding reform in the medical profession. Contrary to what Donaldson says, there is no obvious 'action flowing from [parents'] experiences'. Parents could have responded to the news in a number of ways - they could have seen it as an unfortunate mistake, or the result of doctors not wanting to upset them at the time.

That particular parents have come to see their experience as the consequence of the 'arrogance' and self-regulation of the medical profession, demanding new legal standards for doctors, is something that needs to be explained.

Right from the beginning, parents' groups have had a close relationship with government ministers and 'modernising' members of the medical profession. Michaela Willis (ex-chair of BHCAG, today chair of NACOR) says that she first met her local MP Nick Harvey to discuss the issue in 1996 - today she speaks with around one government minister a week. Both BHCAG in Bristol and Pity II in Liverpool spent substantial time over a number of years working with the official inquiries - contributing evidence and discussing the problems and situation of organ retention and child heart surgery in the NHS. Their views and understanding of their particular experience are likely to have developed during their regular meetings with the government-appointed committees at Bristol and Liverpool over this extensive period.

The fact that parents' groups were funded by the Department of Health (DoH) also indicates a close relationship. According to Willis, the BHCAG was originally given a

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grant of 'about £20,000' from the DoH. She said that NACOR, founded in December 1999, was given an original grant of £32,000 'within two months', and a subsequent £10,000 later. The Alder Hey group Pity II was given money by the DoH inquiry into organ retention at Alder Hey.

Another important influence over the development of parents' groups has been the media. Michaela Willis described how she got into campaigning around the Bristol scandal: 'In April 1995 I saw on TV that nine out of 13 children had died after an arterial switch at Bristol...I was put on the TV the next day and in the newspapers...then *Dispatches* came next, and various other things.' From the beginning, the media promoted both the issue itself and certain parents as public representatives. 'The media backed us tremendously well all the way through', said Willis.

Media publicity meant that the issue began to take off, '[It] took on a life of its own, because children sell newspapers', said Willis. Parents began to contact Willis, to find out if their child could have been affected - she decided to set up a campaign group with the aim of 'finding out the truth'. '[We] wanted a full public inquiry. Because there had been so much media speculation, yet there wasn't anything to back it up.'

The media platform has grown bigger and bigger over the past few years. Today, as chair of NACOR, Willis speaks to 'at least one' member of the press each day: 'When something happens [the story reappears in the news], I come back to find 20 or so messages on my answerphone.' But the development of parents' groups cannot be laid at the door of politicians and the media alone.

Willis says that she received 19 phone calls from parents in the days after she appeared on TV in 1995; in less than two years, NACOR has received about 16,000 such phone calls. The BHCAG began as a handful of families; Willis estimates that most of the 300 families who the BHCAG represent turned up to the last annual general meeting to elect the new committee. It seems that there is a growing interest among people whose loved ones may have been affected by these scandals to act on the basis of their grief. (Lawyers then encourage parents to translate this grief into a claim for compensation - a class action is currently being brought against the NHS on behalf of parents whose children's organs were retained, and compensation bills could be for up to £30million (6))

NACOR has developed a fairly impressive structure. According to Willis, it has three-monthly meetings, 16 satellite groups, 4 regional coordinators, and a quarterly newsletter received by 2000 people. It has travelled around the country to 11 different regions, running public seminars on the question of organ retention. In an age where many collective organisations like trades unions, the church and civic organisations are in decline, NACOR stands out as a growing organisation.

People become involved in parents' groups for reasons that are genuinely felt - not because they are consciously acting as a cynical front for a government agenda. Willis is candid, open and driven by what she sees as a worthwhile mission. 'We were very fortunate', she says, describing the surprising amount of DoH funding NACOR received. 'I don't know if it was because I was reasonably well known by then...' Nor is she a mere pawn - she comes across as determined and capable, and is, I imagine, a very good lobbyist.

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There seems to be a strong element of the social campaigner to many of those at the forefront of parents' groups - the leaders speak stridently for change on behalf of the public. Representatives who spoke at the chief medical officer's conference called for 'the need for change' and to 'raise the general awareness across the nation'. One

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member of Pity II told me that the group had the aim of ensuring that 'human beings are treated with utmost respect and dignity'.

But the parents' role as social campaigners is grounded in their private experience of grief - it is their experience of losing a child that transforms them into public spokespeople. The growth of parents' groups around Bristol and Alder Hey, then, perhaps also says something broader about the mood in our society. According to John O'Hare from Pity II, 'The one common factor between us is that we have all suffered the most painful loss'. It seems that one of the few ways that we can relate to others today is through our shared suffering. And one of the few ways people become motivated to campaign for a cause is as a result of their experience of grief.

The danger is, however, that this popular sentiment leaves people open to the manipulations of politicians, their allies in the medical profession, and the media.

Read on:

[After Bristol: the humbling of the medical profession](#), by Dr Michael Fitzpatrick

(1) Chief medical officer's summit on organ retention, 11 January 2001. Click [here](#) to download a copy of the transcripts in .pdf format

(2) See the [Pity II](#) website

(3) See [After Bristol: the humbling of the medical profession](#), by Dr Michael Fitzpatrick

(4) See [The New NHS](#)

(5) [Supporting Doctors, Protecting Patients](#)

(6) [The high price of Alder Hey](#), by Dr Michael Fitzpatrick



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